

**TITLE**

Living with limb loss: Everyday experiences of 'good' and 'bad' days in people with lower limb amputation

**AUTHOR**

Day, Melissa; Wadey, Ross; Strike, Siobhan

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## **Abstract**

*Purpose:* To provide an understanding of the everyday experiences of individuals with a limb amputation. *Method:* Twenty-two participants (14 female, 8 male) with a mean-age of 42 years ( $SD = 10$  years) were recruited to take part in two focus groups. The participants reported a range of lower-limb amputations (i.e., congenital, acquired, transfemoral, transtibial, unilateral, and bilateral) and on average were 5 years post-surgery ( $SD = 7$  years). Each focus group comprised of 11 participants and was moderated by either the first or second author. The moderator asked participants to discuss their everyday experiences of life with an amputation using Charmaz's good day/bad day approach. Focus groups were transcribed verbatim and analysed using an inductive thematic analysis. *Results:* Four themes were identified: pain, organization and planning, the embodied experience after amputation, and interactions with others. *Conclusions:* These themes provide a key resource for understanding daily fluctuations in physical, social, and psychological functioning.

## **Introduction**

Every year in England around 5000 major limb amputations are carried out, most often precipitated by cancer, vascular diseases, complications of diabetes, or serious trauma [1]. While there is no up-to-date published information available about the worldwide prevalence of amputation, amputation rates have not decreased over the last decade. For example, in 2005, 1.5 million people were estimated to be living with limb loss in the United States of America, by 2050 this rate is projected to double to 3.6 million [2]. Conversely, despite advances in medical treatments the procedure is likely to become more common, particularly given the aging population and increasing incidence of diabetes.

While amputation may be a lifesaving procedure, the resulting impact of amputation can be life changing, presenting the individual with adjustments in almost all aspects of daily living and functioning [3]. In addition to coping with physical changes such as impaired balance and mobility [4], pain, and discomfort [5], individuals with an amputation also face a number of social and psychological challenges [6]. Researchers exploring these challenges have often described the embodied experience after amputation, including coping with identity changes, body image anxiety, the meaning of using a prosthesis, negative reactions and feelings about their amputation, and social discomfort [6-8]. Further, researchers have also identified that experiencing difficulties completing basic skills and daily activities may cause individuals with an amputation to report a loss of independence, feelings of inferiority, decreased well-being, and difficulties coping with their changed identity [6]. Consequently, it is unsurprising that people with an amputation may be vulnerable to experiencing anxiety and depression, particularly during the initial stages of their rehabilitation [9].

Given these negative experiences it is understandable that much of the literature on amputation and more widely on trauma and disability has been grounded in an illness ideology, emphasising barriers to recovery and focusing on negative experiences [3-8]. Yet the result of this narrow focus is that treatment 'success' has most often been determined by an absence of symptoms, a benchmark which is not synonymous with the patient's ability to live a happy and fulfilled life. Consequently more recently there has been an emergence of research underpinned by positive psychology. This approach does not ignore the difficulties experienced after amputation. Instead it posits that through the process of suffering from adversity, changes may arise which advance the individual to a higher level of functioning than that which existed prior to the adverse event [10]. Indeed research has demonstrated that the use of strategies such as positive reframing, support seeking, and humour may contribute to feeling psychologically strengthened after amputation [11].

These two quite distinct research areas, grounded either in positive psychology or exploring the negative consequences following amputation, illustrate the diverse array of responses associated with life following an amputation [11]. While historically research has consistently associated limb loss with numerous psychological difficulties, as we outline above more recent perspectives have shown that some individuals may view their experience in a more positive light. Yet this depiction of such diverse experiences may not only suggest that some individuals are more adept at coping, but that the same individual may experience both difficulties and positive experiences. From this perspective, it may be suggested that strategies used to cope with a limb amputation may fluctuate over time and in accordance with environmental demands and personal resources [12]. Thus an individual may describe experiencing psychological difficulties when the environment is not conducive to

coping, yet may also describe alternative environments which stimulate more positive experiences. Such fluctuations might occur on a long-term basis (e.g., reporting more positive experiences when moving to suitable accommodation) or on a short-term basis (e.g., feeling strengthened by having lunch with a friend). Most often, the literature has focused on the overall long-term experience after limb loss [6]. Consequently, in this manuscript we focus on those positive and negative fluctuations that may be evident in the ordinary, everyday experiences of individuals living with amputation.

Everyday experiences characterize the mundane and commonplace activities of our daily lives, representing who we are, where we are from, and what purpose we have [13]. These daily experiences have been suggested to be fundamental in allowing individuals to maintain independence, quality of life, and life satisfaction [14]. Further, central to our understanding of everyday experiences is the idea that these experiences are embodied interactions with the world, allowing meaning to emerge through our interactions [15] as well as lending new meanings to the future [16]. In particular, the work of Charmaz [16] provides a valuable illustration of the daily experiences of individual's living with chronic illness and disability, highlighting the novel and fluctuating rules, rhythm, tempo and time changes that may guide everyday life. Yet research exploring these everyday experiences in disability has been limited and calls for a greater understanding of the everyday lives of individuals with a disability have been made [17, 18].

One method of understanding everyday experiences is demonstrated through Charmaz's depiction of 'good' days and 'bad' days [16]. She explains that for individuals with chronic illness or disability a 'good' day permits an even schedule and is savoured, while a 'bad' day forces the individual to attend to their immediate

needs and may be dreaded. In line with Charmaz's approach, a number of studies in the field of health psychology have utilized the concept of good day/bad day to illuminate the everyday experiences of individuals with a variety of health conditions including children of a parent with psychiatric disability [20], people with cancer [21], and people with dementia [22]. These studies have demonstrated the rich source of information that can be gained by understanding everyday experiences as well as the valuable clinical implications that these everyday experiences have for improving quality of life for patients and their caregivers. In particular, understanding fluctuations in everyday experiences may provide valuable practical information to guide strategies used by health care practitioners involved in patient management. Further, such information may also provide recommendations at a policy level, whereby many existing policies (e.g., Personal Independence Payment, a benefit for individuals with a disability in the UK) rely on evaluations of daily living and mobility activities.

Given the limited research attention on the everyday experiences of individuals with an amputation and the potential clinical and policy implications, the aim of the current study was to explore these everyday experiences in this population using a good day/bad day approach.

## **Methodology**

### **Participants**

Following institutional ethical approval, recruitment for this study took place at a rehabilitation event for people with an amputation. This rehabilitation event was a voluntary one-day event, which allowed people with an amputation to meet and share experiences with others, as well as providing information delivered through workshops on strengthening exercises, self-care, and health and nutrition. Participants

were informed of the opportunity to participate in a focus group prior to the event but were not recruited until the day of the event. On enrolling in this event, participants were provided with information on the current research project and informed that their participation was entirely voluntary. In total 22 participants were recruited who all gave informed consent. Two people who attended the rehabilitation event declined to participate in the research, they were not asked to provide reasons for their non-participation.

As shown in table one, 14 participants were female and 8 were male. The mean-age of the sample was 42 years ( $SD = 10$  years). The participants reported a range of lower-limb amputations (i.e., congenital, acquired, transfemoral, transtibial, unilateral, and bilateral) and on average were 5 years post-surgery ( $SD = 7$  years). Five participants were temporarily wheelchair bound and two participants were walking with the aid of crutches, this was due to reasons such as blistering and infection. All participants reported that at some point in their rehabilitation they had been a wheelchair user. No individuals with upper-limb amputations accepted our invitation to participate.

[Table 1 near here]

### **Data collection**

This study was underpinned by ontological relativism (psycho-social phenomena are multiple, created and mind dependent, as opposed to existing independently of human conceptions and interpretations) and epistemological constructivism (knowledge is constructed and fallible). We elected to use focus groups as they may be suggested to provide a valuable method for encouraging participants to share mundane, everyday experiences that may otherwise be missed in a one-to-one interview. Focus groups generally range in size, from between 4 and 12 people, with smaller groups allowing

each individual more of a voice while larger groups have been suggested to elicit more ideas [22]. In line with the aims of this study, we elected to divide our participants into larger focus groups, potentially allowing a wider range of experiences to be discussed. Thus participants were allocated into two focus groups with 11 participants in each group. While larger groups have been suggested to inhibit the free flow of discussion [23] this limitation was less relevant to our sample as participants were familiar with each other following their earlier participation in the rehabilitation day. In allocating participants into each focus group we aimed to consider homogeneity and heterogeneity across the two groups. Given the small number of males in our sample we allocated 4 males into each focus group. Female participants were then allocated into a group with consideration of their level of amputation, age, and years post amputation. While such considerations were important, our primary aim was to ensure that participants felt comfortable in the group they were placed into, thus personal preferences were also accounted for. Where participants requested to be part of a specific focus group then this request was granted, we thereby adopted a flexible approach in order to ensure that the focus group experience was positive for our participants.

Each author acted as a moderator for one of the focus groups. Both authors had over 10 years of experience in interviewing participants who had sustained life-changing injuries as well as conducting focus groups, both had completed PhD research in relevant areas of study, and both had engaged in further professional training on working with populations following trauma. The authors were not part of the treatment team for any participant and were not known to participants prior to the rehabilitation event. Both authors were present for the duration of the rehabilitation



event in order to greet potential participants, answer any questions about the focus groups, and build rapport.

Participants were welcomed into the group and were seated in a circle to allow eye contact between all group members. Each focus group began with what has been described as a ‘grand tour’ question [24], as the moderator asked participants “tell me about a good day for you”. Where needed curiosity-driven follow-up questions [25] such as “describe what a good day looks like” and “what might you do on a good day” were used, although the free flow of discussion within the group meant that the moderator had a minimal role. When all conversation on good days had been exhausted participants were then asked by the moderator: “tell me about a bad day for you”. Again, similar follow up questions were occasionally used by the moderator. Focus groups continued until all conversation had been exhausted, with each focus group lasting approximately two hours. Both focus groups were recorded and transcribed verbatim.

### **Data analysis**

The data were analysed using an inductive thematic analysis [26]. First, the transcripts from the two focus groups were read, considered and discussed by both authors to gain familiarity with the data. In doing this each author offered their perspective to the other as moderator of the group and impressions of emerging themes and patterns were discussed. Second, the first author generated initial codes by identifying interesting features of the data in a systematic fashion. Next, data relevant to each code was collated, considering how codes might be combined to form an overarching theme, how themes linked together, and how well each theme represented the central focus of the stories that emerged from the group. Finally, themes were named, defined, and then refined throughout the writing process.

Throughout the analysis process the second author acted as a critical friend, engaging in critical dialogue and encouraging reflexivity by challenging the construction of knowledge [27]. The purpose of this was twofold. First, it allowed the researchers to reflect on and discuss whether saturation had been achieved. In line with Charmaz's (2014) approach to saturation [28], we considered saturation to go beyond merely 'nothing new happening' in our data (P215) and instead evaluated whether categories identified were rich and had conceptual depth. While the concept of saturation can be problematic for researchers given the lack of guidance around applying saturation [29], the use of a critical friend allowed us to reflect on the range of evidence that could be drawn from the data, the connections between themes, subtlety and richness in themes, and resonance with the literature. When both researchers were confident of the readiness of the research for the final analytical stages, the second role of the critical friend was to provide a theoretical sounding board to reflect on and explore alternative explanations and interpretations as these arose.

In line with our relativist approach, we did not seek to use apply any universal criteria to develop rigour in our work, but instead drew on methods of enhancing rigour most suitable for our research which, in addition to our use of a critical friend, also included gathering informal member reflections through ongoing discussions as themes developed. This involved sharing and dialoguing with our participants about the study's findings and providing opportunities for feedback and insight, thus further co-constructing and crystalizing the identified themes. In doing this we were able to generate more nuanced insights which ultimately led to more well-rounded themes.

## **Results**

In this section we proceed to explore four main themes that characterize a good or bad day for our participants: pain, organization and planning, the embodied experience after amputation, and interactions with others. In discussing each of these themes we present how these were experienced, both on a good day and on a bad day. In doing this we highlight that while similar themes were discussed on both good and bad days, it is *how* these were experienced that denotes the type of day. Thus what makes a good day is not simply more (or less) of what occurs on a bad day, but is dependent on the meaning associated with events and the coping resources available.

### **Pain**

For all of our participants, stories of both good and bad days were contextualized within the everyday experience of pain. This pain was most often attributed to minor falls, phantom leg pain, pressure sores, and swelling. While some participants reported that a pain-free day was possible, for most a good day involved better management of pain, allowing them to engage in activities that they *wanted* to do. These desired activities included walking, socializing, playing sport (e.g., amputee football, running) and learning something new (e.g., training course at work), resulting in laughter, fun, and joy. In order to manage pain, participants described that on a good day they used these desired activities to distract themselves from pain. Such strategies resulted in less rumination about pain. As Sarah described:

I went to this party and sometimes you think oh my leg hurts and it's uncomfortable and I just have to stand talking to everyone pretending my leg doesn't hurt. This time I thought I'm going to make a rule that instead of just standing in a corner like I sometimes do, I'm going to go round and I'm actually going to work the room. At the end of it I realized I hadn't thought about my leg the whole evening and I felt good.

On a good day participants were not only able to take part in desired activities despite their pain, but also participated in activities that held the potential to cause them future pain. Thus on a good day, pain was perceived as acceptable since it occurred as a result of a worthwhile activity:

[George] If I'm going to have pain then it's going to be worth it. When I get home at the end of the day I'm going to look back and go 'I'm glad I've done that. I'm glad I actually walked through it'.

[Anna] I can't let pain define me and stop me from doing what I want to do.

In line with this, participants also described that on a good day they were able to learn from their pain:

[Josh] Sometimes that pain might direct me to what I need, something I know I need to do. So how I think about that pain changes sometimes. If there is a strategy to deal with that pain and I can do something with it then it tells me that I need to strengthen something or I need to do something, then it [pain] is ok because I can learn from it.

[George] It's worthwhile having that pain isn't it, if it's going to give you an end goal, something that you can actually move forward on to.

In contrast, on a bad day, descriptions of pain often started from the time participants awoke: "a bad day for me is when I wake up in pain, my day hasn't even started and my leg feels swollen" (Jason). Furthermore, in an effort to control this pain, participants described the difficulty of feeling alert in the morning while taking pain medications: "Mostly I have been struggling with phantom pain. So you know I will be taking medication, groggy and I need to get up, I've got work to do and that affects it, and you get into a spiral" (Steph). These descriptions highlight that pain on waking was often critical to whether participants experienced a good or bad day. As Susan

described: “If I’m not in pain then that’s going to set me up for a good day”. In particular, the critical role of pain in forecasting a good or bad day was attributed to being unable to control pain levels, even when taking medication. Thus waking in pain often resulted in a bad day because the only source of pain management was to limit movement and activity. As Gloria described:

Pain is almost like the one thing I can’t control and therefore it dictates how I go about the day. If the pain is manageable then maybe I’ll do certain things, but maybe if it’s on a 6 or a 7 then I know I have to sit down to take my leg off and that restricts your movement.

As a result of their pain participants often described that a bad day left them feeling unable to leave the house and unable to engage in hobbies, interests, and leisure activities such as walking:

If I have lost sleep or if I’ve done something silly and I’m bruised or in pain, when I wake up in the morning it will just be a case of you know rather than going out walking this morning, I will go and sit on the balcony. Rather than going out, I will do the washing, or something else that needs doing (Linda).

As the above quotation illustrates, on a bad day leisure activities such as walking were often replaced with more mundane household tasks. The need to complete such tasks despite being in pain was a common difficulty among participants:

[Louise] Pain affects everything.

[Penny] Like sleep at night time, at night the pain will be so much more.

[Jason] And what meds [medication] I have taken, that will affect me as well.

[Jill] So I don’t sleep all night and then we are on the next day, I have got to get up, get the kids to school, and everything else. It is just getting to that next day and here we go again.

[Deepak] Because pain is massively, massively tiring.

[Louise] In fact it preoccupies you, it's distracting, it's a struggle.

[Deepak] I mean eating I find, I can't eat properly.

[Carly] It's a struggle just to do the things that you should be able to do without thinking, like walking to the shop.

[Penny] The hovering.

Despite the consuming nature of pain, participants' descriptions of a bad day included daily activities such as childcare and housework that they described as something which *should* be completed despite their pain. Thus pain became the backdrop to stories of a bad day which depicted the struggles to complete necessary everyday activities. Further, while participants were able to feel some achievement in completing these everyday activities, their sense of enjoyment was low:

[Simon] You can get some satisfaction by just getting through the day, but getting there wasn't enjoyable and I suppose there is a difference between enjoying the day and feeling at the end that you have achieved something. For me, the achievement doesn't over-ride the fact that I didn't enjoy the process. I have to enjoy the process as well as the achievement.

[Mary] You can still achieve but actually...

[Simon] ...I will still have a sense of achievement but you look back and think thank god that day is over, I didn't enjoy it at all.

As the participants above describe, while pain was a constant feature on both good and bad days, the meaning of pain fluctuated on a daily basis. On a good day pain was described more positively, resulting from worthwhile activity and directed treatment or rehabilitation strategies. In contrast, waking in pain often resulted in a bad day,

which limited desired activities and left participants struggling to complete everyday household tasks.

### **Organization and planning**

Participants described that being a person with an amputation and at times also a wheelchair user required them to engage in substantial planning prior to any activity or journey that was undertaken. This planning formed the backdrop of all daily activities that took place outside of the home. While the amount of planning required remained consistent on a good or bad day, the associated meaning and sense of achievement in overcoming obstacles varied considerably. On a good day, participants described the journeys that they undertook with a sense of determination:

[Penny] I've now become a wheelchair user for long distances so it's rediscovering how do I actually get there.

[Mandy] It might be the long way round.

[Penny] You have to think of curbs and other bits and pieces, it's a whole voyage of discovery again.

[Mark] So it's planning your route, so you think there is a massive hill up there with railings going around, there's no way my chair is going to get up there. I'm going to have to go the long way around. It might take me another 10 to 15 minutes but hey, I got there.

[Penny] That's right.

As demonstrated in the above discussion, participants highlighted that despite the familiarity of many journeys, life after amputation required 'rediscovery'. On discharge from hospital after their amputation participants described experiencing numerous difficulties including that "suddenly you realize the ground isn't even everywhere" (Susan) and "the reality of it [hospital discharge] was bloody awful,

because there weren't people there to help me" (Sarah). Yet over time they described learning to mentally visualize journeys and utilizing prior knowledge of the landscape and experience of their own capabilities to anticipate potential barriers. On a good day this rediscovery was perceived as a challenge, yet on a bad day participants described their frustrations with the amount of time and physical effort needed to navigate the environment:

You know getting off my drive, it's a gravel drive, in a wheelchair it's an absolute nightmare without help, and so then you don't bother. It is the freedom taken away from you, because it takes so much more effort to do what you might have wanted to do that day. You end up thinking I'm just not going to bother, I'm writing this day off. I will try again tomorrow, and it's infuriating, you feel like it's a waste of a day (John).

In particular, on a bad day participants described their resentment of the organizational and environmental barriers that they faced. In illustrating these barriers, comparisons were made between the complexity of everyday experiences as someone with an amputation and the ease and spontaneity of being able-bodied:

I have just started swimming again and to go onto the poolside I have to have the things to take my leg off with, my cover for my sock. Then I have to remember the goggles, towels, and all the other things to go swimming with. Every time I go there I sit down and I've forgotten something. So you go back to the changing room to pick it up and bring it back. But it's not just that, you go off and you do it like you used to and now it annoys the shit out of me that I have to constantly think about where I'm going and what I will need that is extra to the other stuff that everybody else will take with them. And I know it should become second nature, it's just very frustrating. (Steph)



As the above quotation illustrates, planning activities as an individual with an amputation included both visible preparation (e.g., additional equipment needed, revision to journeys) as well as invisible preparation (e.g., considering what if's). Thus participants highlighted not only the additional physical effort required but also the additional cognitive effort. Participants described feeling defined by their lack of spontaneity "this is what going to define my life, is this what my life is going to be all about, am I going to ever going to be able to lead near to a normal life", comparing the demands of their life to those of able-bodied friends and family:

[Simon] I want to get up and get a glass of water, and they [family] can just get up. The amount of times I have missed a postman, or the phone ringing and I'm not in the right room. And it gets the point where I get up and think...

[Gloria]...I'm not going to get that.

[Simon]I know I'm not going to make that so I'm going to let it ring out.

[Anna] And the postman is like, bang, bang, bang, bang, you know three seconds later, a card has come through, I have been waiting in for that.

[Simon] And the sorting office is miles away, how am I going to get there?

As the above description illustrates, the difficulties experienced not only impacted desired activities and journeys but also everyday mundane household tasks. While participants described their enhanced planning skills, they acknowledged that some tasks were more difficult because they were unexpected or in need of rapid completion. While successfully navigating barriers through effective planning could lead to a good day, in contrast bad days were most often characterized by feeling overwhelmed by the time and effort needed to plan, as well as the difficulty in taking spontaneous actions.

### **The embodied experience after amputation**

Participants highlighted the crucial role played by the body in shaping their experiences of a good or bad day. In similarity to their experiences of pain, participants described that on a bad day feelings of vulnerability and self-consciousness about their physical body often started from the moment of waking:

Once I have got my legs on, I almost feel like I could get on with what I want to do. Yes things feel a bit different but you start to learn to try to adjust. But it's that initial getting out of my bed to put my legs on, that's the one time I feel so vulnerable, it's the way it looks as well, I have got no legs. Once I get myself on to the legs, I'm alright, but it's actually finding the strength sometimes to get out of my bed to put those legs on.

As illustrated above, vulnerabilities were often associated with not wearing prosthetic limbs. This suggestion was further emphasized when participants described that on a good day they felt comfortable removing their prosthetic limb in front of others. One such example of this was shown in their description of being at the rehabilitation day:

[Philip] A good day is when I just feel like everybody else.

[Gloria] Moving away from the amputation.

[Michelle] I also find being able to be myself. You know sometimes you go somewhere and you know the people aren't going to react terribly well if I suddenly pop my leg off [laughing]. I'd better wait.

[Philip] That's the best bit isn't it [laughing].

[Michelle] It is. I love doing that.

[Linda] So when we all sit down to lunch I can quite happily pop my leg off, chuck it on the side and no-one even blinks about it. It's nice to be in an environment where you don't have to think about that.

Participants agreed that they were more likely to experience a good day when they were open about their amputation with others. Yet for many, the confidence to visibly display their amputation took some time post amputation. As one participant described:

I think for me the change that allowed more good days was the day I took my cover off my leg. I wanted so desperately to be normal and it used to get in the way. It wouldn't swing properly and so the day I took that cover off I also cut my leggings off so everybody could see it. When actually took that step out and went actually I am an amputee, this is me, it was like oh gosh, I wish I had done that such a long time ago (Sarah).

In particular, participants described the emotional impact of being able to show their prosthesis to others: "I kept everything inside and nobody knew how bad I felt and actually when I could reveal it physically on the outside, actually what happened on the inside also changed, you know the two almost go together" (Mandy). Further, they suggested that being open allowed them to initiate conversations with others, or allowed others to learn about their physical body. As Amanda described: "I put my swimming leg on and this one kid was just looking at me. I think he was a bit afraid but I said you know, it's fine, do you want to have a look?"

Despite the desire to be accepting of their physical body, participants described that one of the main barriers to this was the clothing they were able (or unable) to wear. This was often suggested to trigger a bad day:

[Sarah] I want to feel attractive, smart, feel good, participate, but I can't find shoes that feel comfortable, I don't like what I have got in my wardrobe.

[Linda] You just want to feel good about yourself.

[Susan] Maybe women notice these things more than men I don't know?

[Sarah] Honestly, it is not to do with what other people think of me, it's just that on a bad day I look in the mirror and I think oh my god, should I really be going out today, you know and that is how I feel.

Those days described as most difficult were when participants were involved in social events which required them to dress more formally. In particular, females with an amputation highlighted the difficulties associated with wearing flat shoes:

I suppose it's a female thing but if you are invited somewhere and it's a posh do and you're getting dressed up and then you look down at your shoes. And then it's like bloody hell, from here [head] to here [knee] I look ok, and then I have a pair of trainers on my feet. (Carly)

Females with an amputation described that not being able to wear heeled shoes made them feel "dowdy" and that attending social events prompted them to feel more self-conscious about their amputation:

I'm trying to enjoy this lovely occasion [wedding] and I want to be happy for them, but actually I'm putting on a front because I'm not enjoying it at all, and I suppose I'm thinking about what I look like, it has become more of an issue as an amputee, I wouldn't have worried so much before I was an amputee.

Probably wouldn't have even thought about it. (Sarah)

Males with an amputation were not immune from experiencing difficulties associated with clothing. In similarity to their female counterparts they noted the difficulties of dressing smartly "I was the worst dressed bloke in the place, there with scruffy cargo shorts" (George). This difficulty was ameliorated on occasions when there was a dress code:

First time I went out for birthday drinks after my amputation, my friend took me to a really nice bar. I discovered that the extra socket around my knee

meant that none of my smart trousers fitted nicely. I thought I can't go clubbing in shorts, but in the end I had to. You end up having to try to explain the intricacies of amputation to a doorman who doesn't care, just because they have got a 'no shorts rule' and trousers aren't practical. I just said to them that we have got to make this work, come on. (Samuel)

As the above descriptions illustrate, being a person with an amputation often required participants to dress in a particular way (wearing flat shoes, trainers, shorts) which facilitated them to be more physically mobile or reduced their pain. Yet in doing this participants also described the difficulties of violating social norms associated with clothing, causing them to feel self-conscious, under-dressed, and for females, unfeminine. In line with this, participants described that good days were most often experienced when clothing norms were better suited to their needs after amputation (e.g., playing sport in trainers). Further, when their amputation was not immediately visible because of their choice of clothing, participants described that others often did not recognize their amputation. For example "someone trying to guess which leg is false, that's always good when you're wearing trousers" (Philip) and "When people say 'I never knew you were an amputee', I love that that's great" (Mary). Thus participants highlighted the crucial role of the body in determining good and bad days, from the vulnerabilities associated with not wearing a prosthetic limb, to the decisions and efforts required to reveal or conceal their prosthesis.

### **Interactions with others**

Participants described that their relationships and daily interactions with others had a strong influence on whether they experienced a good or bad day. The kindness of others, particularly the general public, was often suggested to contribute to a good day. For example:

[Penny] Something that makes me feel quite happy is, because I'm sitting in a wheelchair, it the kindness of other people. Especially on British rail or London underground... The amount of people, passers by, strangers that just ask 'are you alright there?' and sometimes you come home and think wow, it gives you some sort of feeling like there are good people out there.

[Mark] When people put that effort in when actually they never had to. I'm not asking for your help but actually you don't mind going past and checking I'm ok. You have put yourself out and actually that makes me feel quite worthwhile.

[Jill] Yes, it is really nice, and even in supermarkets when people think you are struggling. Sometimes people say 'I didn't know whether to ask or not'.

Here, participants illustrate that acts of kindness from strangers made them feel valued. In particular, their descriptions focused on times when they did not ask for help completing daily tasks, but where their disability was visibly evident (e.g., when using a wheelchair). In line with this, participants also described that repaying such actions and providing help to others also made them feel valued and provided a more balanced approach to giving and receiving help:

[Louise] It's being asked to help, rather than people assuming that you can't.

[Carly] So I think that's the first thing, somebody saying, 'can you look after my child?' As opposed to 'oh you can't do it'. So I think that's the first thing. And then actually being able to do it and feeling that you are giving something to somebody as opposed to just being the receiver all the time.

In particular, participants described the feeling of being a "burden" to others and highlighted that this could be overcome by providing a valuable contribution:

[Philip] They talk about disabled people, feeling like they are a burden, don't they.

[Simon] So if you feel like you are valuable member of society that is a huge positive.

[Sarah] A valued contributor, recognized, it's rewarding.

[George] Yeah, that you are a value as a person rather than...

[Philip] ...A burden

[Michelle] Yeah, you're a giver rather than a taker.

In addition to giving to others, participants also suggested that good days often occurred because others had belief in their abilities. This was shown through the leisure activities suggested by others (e.g., "shall we go for a walk") and when others encouraged them to push beyond their physical capabilities. As Samuel described: "I'm not just me, I'm part of a family, and if I don't do things my family don't do them, my kids can't do them...I've had to just get on with things". Good days most often occurred when family members did not make concessions for them, allowing them to continue to uphold their role within the house and the family. First this was illustrated through the completion of established physical tasks:

The dog barks in the middle of the night and I have to get my leg on and go and see to it. Why shouldn't I take my role with my wife and my two kids, why should it always be someone else? (Jason)

Second, this was also established through the emotional response from family members:

I should have bought my family here cos from day one they have refused to treat me as any different, because they know how lazy I can be... My wife is

wonderfully brutal with me, she works on the basis that you will get sympathy if you need it, and I don't think you have ever needed it. (Samuel)

In line with this, participants described that bad days could occur as a result of feeling patronized by others. Specifically this occurred when others congratulated them for tasks perceived as easily achievable:

I've always been keen on adventure sports and I walked up Snowden and at the end I thought I did not enjoy that at all. It felt unnatural, it felt like I was forcing myself to do something that I didn't want to do... I got up it but I didn't feel any sense of achievement, my friend was going 'oh well done', I felt patronized because they are going 'well done' on something I would have done without even thinking. (Sarah)

Yet as the above example illustrates, the achievability of tasks was often measured by the yardstick of what could be achieved before amputation rather than the physical difficulty of the task. Consequently on a bad day while participants valued the support of others, statements often intended as esteem support and encouragement were interpreted negatively as concessions for their amputation. Thus good and bad days were distinguishable first by the balance of giving and receiving help, and second by the perceived concessions made for their amputation by others.

## **Discussion**

The aim of this study was to explore the everyday experiences of individuals with an amputation by understanding what constitutes a good or bad day. In doing this, this study extends current literature by presenting new findings on common, everyday experiences. Consequently, unlike many studies that have used one-to-one interviews to ask participants about more 'memorable' moments, our focus groups concentrated on everyday experiences that may otherwise be missed, but which may also be



proposed to represent how those with an amputation spend most of their lives. As little is currently known about how individuals with an amputation experience everyday life our findings provide novel insights into how life is actually lived.

Our results extend previous research by illustrating four key themes which encapsulate everyday life for individuals with an amputation: pain, organisation and planning, the embodied experience after amputation, and interactions with others. For our participants, these themes provide the backdrop to daily living and our results demonstrate the crucial role that each played on a good or bad day. For clarity each theme has been presented separately, but it is important to note that these act together, interweaving to provide a rich tapestry in which everyday experiences are framed. For example, participants described the *embodied experience* of waking up without wearing prosthetics, illustrating that this was when they felt most vulnerable. Time lying in bed was often used to consider their levels of *pain* and consequently to forecast the type of day that would ensue and activities that could be managed. Lower levels of pain often resulted in a more determined approach to *planning*, allowing participants to take part in activities that they wanted to do. Further, participants felt reassured in the knowledge that on a pain free day, *others* would make fewer concessions for them. As demonstrated in this example, while these themes may be classified separately each is influential on the next and in order to represent the reality faced by those with an amputation we must consider their connectedness.

It is also important to emphasize that these themes exist across the spectrum of medical, social, and environmental categories. For example, while pain may traditionally be viewed as a biological event [29], our results demonstrate the social and environmental implications and therefore the cumulative limitations of pain. While the medical model of disability would suggest that bad days may occur as a

result of being in pain and encountering physical difficulties, in contrast the social model would highlight the lack of opportunity (e.g., limited transport), discriminatory behaviours (e.g., others staring), and environmental barriers (e.g., uneven paving) that may cause a bad day. Yet as Martin [29] suggests, both medical and social models of disability emphasise extreme positions and frame each position as mutually exclusive. Here our results emphasise the simultaneous nature of physical impairments and social and environmental barriers, providing support for the social relational model of disability [30]. In line with this we suggest that the type of day experienced may be influenced by a variety of factors that are both social and physical and which fluctuate across time.

Based on our results, a number of novel observations are worth highlighting for each of the themes presented. First, in similarity to other populations who experience pain [31, 32], our participants normalised their pain, suggesting and accepting that levels of pain could predict a good or bad day. On a bad day participants described that their only effective strategy for reducing pain was to withdraw from activity, thus simultaneously limiting their social interactions with others. As previous research has demonstrated, quality of life and self-esteem of individuals with an amputation participating in physical activity will be higher than those who do not participate [33]. Further, in line with previous research [34] our participants recognised the positive impacts of being physically active. Yet conversely, on a bad day, participants focused on those tasks and activities that *should* be completed rather than those which they *wanted* to complete. Such tasks were rarely solely related to participants' own immediate needs and most often involved the requirement to complete household tasks (hoovering, washing) and childcare tasks. Thus participants described that on a bad day they often felt unable to complete activities that may be beneficial to their

own needs (e.g., leisure activities) because of pain or required planning, and instead focused on the need to complete tasks which were required of them and which impacted others. While such a hierarchy of required and desired needs may be understandable, few participants considered the health and psycho-social benefits that may have been gained by attributing more value to leisure time. Such suggestions are worrying given the increased risk of health problems among individuals with an amputation [35] and vulnerability to anxiety and depression [9].

Our results extend previous literature on pain in this population in two main ways. First, they provide an alternative perspective to previous research that has found functional, social, and athletic activity restriction were not factors associated with residual limb and phantom limb pain [36]. This previous research was conducted using a questionnaire design and our focus group approach may have opened up the potential for participants to openly discuss and share more negative experiences of activity in when pain. Second, in line with previous research, our results highlight that while participants acknowledged the benefits of being physically active [34], they struggled to apply this knowledge on a bad day. Worryingly, on a bad day our participants had limited knowledge of any strategies other than activity restriction that would offer relief or solutions from their pain. Understanding daily experiences of pain may encourage medical practitioners to ask individuals with an amputation about the difficulties of living with pain as well as the relationship between pain and leisure activities. Previous pain research [31] has suggested that such considerations are rarely included in consultations which tend to focus more on bio-physiological symptoms of pain.

Second, participants described their frustrations with the need to plan daily activities and journeys in advance. While the need for planning and organization has

been suggested in previous research on individuals with spinal cord injury [37], this has previously been framed as an adaptive strategy for autonomy. Here we do not negate that such planning may assist those with an amputation in being autonomous, but we also highlight the frustrations associated with the amount of planning needed including the time taken and lack of spontaneity. While previous literature has highlight that those with an amputation may experience increased cognitive activity during movement and [34], what has not previously been considered is the increased cognitive effort associated with planning. Of particular note, is that much of the planning required was invisible to others, including mentally imaging journeys and considering possible dangers and risk factors. Such suggestions support previous research that has emphasised difficulties experienced after amputation such as the fear of falling [38] and highlight the hidden impact that this fear may have on the need to plan everyday activities and journeys. While recent literature [39] has highlighted the numerous barriers that may be faced in the physical environment (e.g., personal and communal spaces, equipment, transport) here our results illustrate the importance of considering the additional burden placed on people when negotiating these barriers.

Third, participants illustrated the crucial role played by the body in their everyday experiences. In similarity to previous literature, participants described the embodied experience after limb loss [7] as well as the importance of the appearance of their prosthesis [8]. While our participants did describe their pleasure when others did not recognise their disability, they also acknowledged that self-display of their prosthesis was an empowering action. Yet unlike participants in previous research such as Frank [40] who described that self-display involved the abandonment of their prosthesis, our participants disliked the associated vulnerability of this act, only removing their prosthesis in the company of other individuals with an amputation or

close relationships. Instead self-display was shown through wearing clothing which displayed their prosthesis as well as inviting others to view or ask questions about it. Previous literature [41] has highlighted that individuals with a disability will often strive for a normative appearance, using clothing to conceal or deflect attention from their disability. In contrast, for our participants, clothing that displayed their prosthesis served both a positive functional and psychological role. Yet in wearing such clothing participants struggled to conform to social norms, feeling under-dressed, not conforming to specific dress codes, or (for females) not feeling feminine. While such issues have been previously explored in females with an amputation [42] our results highlight that males with an amputation often shared similar concerns.

Finally, in discussing their relationships with others, participants highlighted the important balance between receiving and giving support. Engaging in altruistic social behaviours by helping others allowed participants to demonstrate their capabilities as well as providing meaningful support. Further, being asked by others for their support reduced the stigma that their disability acts as a barrier to providing help to others. Yet most often, opportunities for supporting others were spontaneous rather than pre-arranged opportunities. As highlighted in the literature [43] people with a disability are often not viewed by the community as potential volunteers, undervaluing their potential contribution. Our results highlight the positive impact of providing meaningful support to others, emphasising that good days were often facilitated by achieving a balance between giving and receiving support.

### **Methodological Implications**

Our results emphasize the value of Charmaz's good day/bad day approach to examining everyday experiences. While this approach has been used with a range of health populations [19- 21] this is the first study to use this approach with individuals

with an amputation. Our results not only endorse the use of such an approach, but also suggest that this approach may be particularly valuable when conducting focus groups, as demonstrated by the rich data collected. Yet we are also wary that qualitative research must strive to go beyond the snap shot interview. Consequently it may be suggested future research might look to further engage with participants through the use of visual methods (such as video diaries or photo diaries [44]) to represent good and bad days, or through more longitudinal investigation (e.g., multiple time points and sources of data collection [39]). Further the themes suggested in this study could be used to prompt longitudinal interviews which explore pain, planning, embodied experiences, and interactions with others over time.

In drawing conclusions from our results it is also important to consider our sample population. First, our results are drawn from two focus groups. While the depth of information gathered from these two groups is evidenced in the rich quotations presented in our results section, including further focus groups may have allowed for a greater diversification of perspectives. Second, our recruitment at a rehabilitation event provided us with a relatively young sample of people with an amputation and a greater number of female participants. It may be suggested that our recruitment strategy led to a sample population who were more likely to engage in help seeking behaviours and who were potentially more mobile (as shown by their attendance at the rehabilitation event and their ability to travel to the event). Our study did not collect socio-economic or mobility data and this may be a consideration of future research. Specifically, future research should aim to explore the good and bad days of a wider range of people with an amputation, particularly those who are less mobile and who have not engaged in help seeking behaviours. Finally, all of our participants were either currently a prosthetic user (but with experience of having

used a wheelchair) or only temporarily using a wheelchair while blisters or infection were healing. Consequently, it is important to consider that references to using a wheelchair within our results are based on those individuals for whom wheelchair use was temporary. Consequently the need to use a wheelchair was often influential during bad days as wheelchair use was associated with increased pain and a decline in physical health. Future research should aim to explore good and bad days in those individuals with an amputation who are not aiming to become a prosthetic user.

### **Conclusion and Clinical Implications**

This research provides the first insight into how individuals with an amputation experience everyday life, utilizing Charmaz's good day/bad day approach. As such it offers a key resource for understanding daily fluctuations in physical, social, and psychological functioning by highlighting the critical role played by pain, planning and organization, embodied experiences, and interactions with others. Our findings make apparent the need to consider the simultaneous nature of physical impairments and social and environmental barriers, highlighting how these may be experienced differently on good and bad days and illustrating the value that health care practitioners and rehabilitators may find in asking patients to describe the dichotomy between a good and bad day. Consequently future policy and decision making that aims to enhance quality of life for those with a lower limb amputation should consider the spectrum of medical, social, and environmental categories. Further, at a policy level, this study highlights that evaluations of daily living after an amputation should be based on a longitudinal assessment. Those policies that rely on one-off assessment negate to consider daily fluctuations across a number of themes that characterize everyday life for this population. Future work should continue to explore everyday

experiences through longitudinal methods, considering how these experiences may change over the life course.

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Table 1

*Summary of Participant Demographic Details*

Pseudonym	Gender	Age	Type of amputation	Years post amputation	Reported reason for amputation	Group
Mark	M	60	Unilateral transfemoral	1	Cancer	1
Jason	M	47	Unilateral transtibial	1	Accident	1
John	M	40	Unilateral transtibial	5	Accident	1
Deepak	M	37	Unilateral transtibial	13	Cancer	1
Mandy	F	42	Unilateral transfemoral	2	Infection	1
Penny	F	42	Unilateral transtibial	4	Blood clot	1
Jill	F	23	Bilateral transtibial	7	Accident	1
Steph	F	42	Unilateral transtibial	11	Infection	1
Carly	F	36	Bilateral transtibial	3	Meningitis	1
Louise	F	41	Unilateral transtibial	3	Accident	1
Amanda	F	54	Unilateral transtibial	27	Cancer	1
Samuel	M	24	Unilateral transtibial	2	Accident	2
George	M	44	Bilateral transtibial	1	Meningitis	2
Simon	M	37	Unilateral transtibial	1	Accident	2
Philip	M	42	Unilateral transfemoral	11	Congenital deformity	2
Sarah	F	56	Unilateral transtibial	17	Accident	2
Anna	F	47	Unilateral transtibial	2	Diabetes	2
Linda	F	59	Unilateral transtibial	2	Diabetes	2
Mary	F	32	Unilateral transfemoral	3	Accident	2
Michelle	F	45	Unilateral transtibial	2	Infection	2
Susan	F	40	Bilateral transtibial	1	Accident	2
Gloria	F	39	Unilateral transtibial	1	Cancer	2

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